



Cook County Hospital
1835 W. Harrison St., Chicago, Illinois 60612-9985. Telephone 312/633-6000

Memorandum - (two pages)

To: Social Security Administration - Attention *to Anne B. Barnhart*

From: Robert E. Johnson, MSW, LCSW, Cook County Hospitals
Elizabeth Fung, DSW, LCSW, Childrens Memorial Hospital

Re: Proposed Rule changes: Revised medical Criteria for
Evaluating Hematological Disorders

Date: Jan, 28, 2002

As experienced medical social workers in Chicago, we have several strong objections to the proposed rules changing the way in which patients with bleeding disorders are considered for disability.

In summary, there is no benefit to implementing the proposed changes, except that of saving the federal government money by making disability payments more difficult to obtain. Several of the new provisions are irrational and would frustrate the purpose of SSI and SSDI insurance.

Proposed Listing 7.03B-Hemophilia contains language that would force parents and patients with hemophilia to implement prophylactic treatment in order to show that "bleeding occurs despite prophylactic treatment." It is inappropriate for the Social Security Administration to be dictating treatment decisions to patients and families. There are many situations in which prophylactic treatment is impossible, such as lack of insurance coverage, lack of venous access, presence of inhibitors or the inability of the family (often a single parent) to manage a complicated medical procedure at home. For families that do manage consistent prophylactic treatment and are successful in eliminating virtually all bleeding, the loss of SSI or SSDI payments is well worth the gain in being able to go about day to day life without the frequent but unpredictable disruptions of an uncontrolled bleeding disorder.



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Proposed Listing 703C-Other Hypocoagulable States, suggests, illogically, that patients should have to prove disability through hospitalizations. Such a provision puts a premium on having patients not learn home care, which is exactly the opposite of the implicit incentives in 7.03B. In general, prophylaxis is just as possible with Von Willebrand's Disease and some other hypocoagulable states for some patients and just as impossible for other patients.

The general provision that there be at least one month between "events" (i.e., bleeding episodes) makes no medical sense. A severe bleed that requires many infusions over the course of a week and several Emergency Room visits and so forth is much more disruptive than several minor bleeds of a month or more apart that may only require one infusion *each* for their resolution.

In summary, there is nothing in our professional experience that justifies making any changes in the disability rules. We have noticed that families receiving disability always have member(s) with severe disorders, who cannot use prophylactic treatment for the reasons listed above or for whom prophylactic treatment is unavailable or ineffective. We have never encountered patients and families who refuse the highest standard of medical care simply because it might make gaining or keeping disability more difficult. As Social Workers, we never encourage anyone to become disabled or even to think of themselves as having any greater degree of disability than is actually the case. We ask only for a system that identifies fairly those people who actually are disabled. The proposed changes move us further from that goal.

Sincerely,

Robert E. Johnson

Elizabeth Fung